DOCUMENT RESUME

ED 163 735 EC 112 803

AUTHOR	Efird, Cathy M.
TITLE	Demographic Analysis and Planning for the Future. No. 13.
INSTITUTION	North Carolina Univ., Chapel Hill. Frank Porter Graham Center.
SPONS AGENCY	Office of Human Development (DHEW), Washington, D.C. Office of Developmental Disabilities.
PUB DATE	Aug 78
NOTE	11p.; DD Themes and Issues: A Series of Topical Papers on Developmental Disabilities
AVAILABLE FROM	DD/TAS, Region IV, Suite 300 NCNB Plaza, Chapel Hill, North Carolina 27514 ($0.75)
EDRS PRICE	MF-$0.83 HC-$1.67 Plus Postage.
DESCRIPTORS	*Data Analysis; Data Collection; *Demography; *Developmental Disabilities; *Futures (of Society); *Prediction; Problem Solving; Program Planning; Research Methodology; *Trend Analysis

ABSTRACT

The basic sources and types of demographic data available for future planning for the developmentally disabled are reviewed and a frame work for data organization is suggested. It is explained that future forecasts may be undertaken by the following principles: trend forecasting or extrapolation; scenario construction; models, games, and simulations; and collection and synthesis of expert opinion. The following types of demographic data characteristics are identified: physical characteristics; morbidity; economic characteristics; social characteristics; and population dynamics. Data limitations are discussed and the problem determinants of human biology, environment, health care organization, and life style are described. The application of methodology to problems relating to developmental disabilities is explained, and the process of drawing conclusions from existing data is examined. (BD)

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themes & issues

A Series of Topical Papers on Developmental Disabilities

Demographic Analysis and Planning for the Future

by Cathy M. Efird

Special Sub-series on the Future

EC112803

Series Editors: Gary Richman and Ronald Wiegerink

Number 13

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DD Themes and Issues is a series of topical papers for this nation's Developmental Disabilities Planning Councils. Each participating state, territorial, and District of Columbia Council develops and implements a comprehensive State Plan for the coordination of comprehensive services for citizens who are developmentally disabled.

This paper is part of a special sub-series on the future and is intended to broaden the vision of the DD Community about the issues and problems which everyone must face in the remainder of the twentieth century.

This series is published by the Developmental Disabilities Technical Assistance System (DD/TAS), which is a consultative and assistance system for the Councils. DD/TAS is a division of the Frank Porter Graham Child Development Center, The University of North Carolina at Chapel Hill.

This series was prepared pursuant to a grant from the Developmental Disabilities Office, Office of Human Development Services, U.S. Department of Health, Education and Welfare. Grantees undertaking such projects under government sponsorship are encouraged to express freely their judgment in professional and technical matters. Points of view or opinions do not, therefore, necessarily represent DDO, OHDS, HEW position or policy.

Typist - Mary N. Watkins

Graphic Design and Printing by
University of North Carolina Printing Department

Published in August of 1978

Demographic Analysis and Planning for the Future

by Cathy M. Efird

> Every person in the world faces a series of pressures and problems that require his attention and action. These problems affect him at many different levels. The majority of the world's people are concerned with matters that affect only family or friends over a short period of time. Others look further ahead in time or over a larger area—a city or a nation. Only a very few people have a global perspective that extends far into the future.[1]

The challenge to acquire a futuristic perspective with regard to developmental disabilities is a pressing need. A five or ten year planning horizon has utility for existing needs but we must, in a simultaneous manner, direct a substantial proportion of our planning resources to future needs. We must become the "very few people" concerned with the future of the developmentally disabled. This orientation will help us not only to focus our energy on specific solutions but also allow us to look for long range interventions that may result in the prevention of developmental disabilities.

In order to meet this challenge, persons concerned with planning for developmentally disabled populations need to become aware of the various ways of looking at the future and of the information available to help them in this undertaking. This paper reviews the basic sources and types of demographic data available for future planning and suggests a framework for its organization. Developmental Disabilities provides a good example of the utility of this approach.

Looking at the Future

Efforts to explore the future in any field are based on the analysis of both existing events and past observations. Information, or data, regarding these situations may be used in a variety of ways to envision the future. Most methodologies rely on the principles of continuity and analogy, in which it is believed that either the condition established in the past will continue as the norm for the future or that the patterns of change observed in the past will repeat themselves in the future. Forecasts based on these principles may be undertaken by any, or all, of the following approaches:

1) *Trend forecasting or extrapolation:* Existing and/or historical trends are analyzed and then projected into the future. Assumptions must be made regarding the future direction of the trend: will it increase, decrease, or remain stable? The major limitations of this approach are the interrelatedness, or mutual dependence, of trends and our inability to adequately quantify these relationships.

2) *Scenario construction:* Various future situations that might occur or that are preferred are created. These hypotheses about the future are based on differing interpretations of existing data and limited only by one's foresight.

3) *Models, games, and simulations:* These often intricate and sophisticated methods provide the opportunity to explore interrelationships among factors influencing the future and to analyze the impact of various actions or changes on these factors. While being

able to use tremendous amounts of information is one of the strengths of these approaches, it is also one of the weaknesses. The technology needed to support these systems is often too cumbersome and expensive for widespread use.

4) *Collection and synthesis of expert opinion:* Many techniques (such as Delphi and Nominal Group) have been developed to introduce human intuition into forecasts of the future. Most approaches rely on the development of a consensus regarding the future among a group of public opinion leaders. Each person is given the opportunity to interpret existing situations and construct his or her own view of the future.

These approaches help us to gain a clearer perspective on the future; they all rely on the collection, analysis, evaluation, and presentation of data. The processing of data may take place in a highly sophisticated manner, such as modeling, or in a subjective and almost random way, such as a businessperson's thoughts.

Looking at the Present

The prerequisite for our excursions into the future is adequate information or data about where we are and where we have been as a population. The formalized study of the data representing these events is demography. Demographic statistics give us information relating to the size, density, distribution, and dynamics of human populations.

In analyzing these components of population statistics, many different characteristics may be studied. Data describing the age, race, sex, and morbidity of an entire population, or of population subgroups, provides information on physical characteristics. The social characteristics of a population may be described by statistics on marital status, family and household structure, language, place of residence, religion, and country of origin. Statistics on income (for both individuals and countries), industrial activity and occupation reflect the economic characteristics of a population. Since populations are not static entities, measures of their dynamics are also studied and include fertility, mortality, migration, and other statistics. The statistics may be aggregated on any number of levels (city, county, state, or nation) and adjusted for any number of variables (age, race, or sex).

Because demographic data represent such a diverse range of characteristics, it is not found in only one source or in any one form. It is possible to list, however, the sources of data by the types of characteristics they describe. The following lists are not meant to be exhaustive, but do represent the major sources of each type of data for the United States.

Physical Characteristics

Age, race, sex, numbers, and distribution:

Census of the Population, Characteristics of the Population
U.S. Census Population Estimates and Projections

Morbidity:

National Health Interview Survey
National Health Examination Survey
Major disease registries (example: National Cancer Registry)
Special publications by provider groups, such as:
National Association for Mental Health

Mental Health Institute
National Association of State Mental Health Program Directors

Economic Characteristics:

Occupation, income, and industry:

U.S. Census Characteristics of the Population and Residential Finance Report
U.S. Labor Statistics

Social Characteristics

Marital status, family and household structure, religion, etc.:

U.S. Census of Housing
U.S. Census Block Statistics
Estimates of Substandard Housing, U.S. Census

Population Dynamics

Fertility, mortality, migration, etc.:

Monthly Vital Statistics Report, U.S. Department of Health, Education, and Welfare, Public Health Service
Vital Statistics of the United States, U.S. Department of Health, Education, and Welfare, Public Health Service

In addition to these national sources, many states issue periodic statistics on various demographic subjects. For example, *Detailed Mortality Statistics Reports* give statewide information regarding the cause of death for each age group; *Basic Automated Birth Year Books* provide useful information on maternal and infant characteristics; and statistical abstracts often present statewide information ranging from the number of households without automobiles to per capita income. The availability of these documents, or ones of similar nature, is quite variable across states.

Special studies often provide useful information for planning, especially in the field of health. The Health Resources Administration within the U.S. Department of Health, Education, and Welfare has recently published a series of documents describing the health status of minority and low income persons in the United States.[2] Several states have completed human needs assessment reports and many others routinely collect and process information to be used for planning purposes similar to the developmental disabilities state plans. Some of the best sources of data are the State Health Planning and Development Agencies and the Health Systems Agencies established through the National Health Planning and Resources Development Act of 1974. These agencies exist in every state and often have a substantial collection of data which relates to the developmentally disabled population.

Data Limitations

Even though data is readily available, good data is often hard to find. Most data have been collected on a random sample basis and are subject to a number of limitations. Bias in the survey may have been introduced through the type of questionnaire used, the technique of the interviewer, or the selection of the group to be interviewed. Many of these same conditions lead to reporting errors, in which respondents under or over-report actual circumstances. Questions regarding the validity of studies are always appropriate since decisions should not be based on information that does not represent the actual state of affairs. The reliability, or reproducibility, of the data must also be tested since being unable to duplicate findings would have implications

for conclusions drawn from the data.

In addition to these technical considerations regarding data, two other limitations are also important. Only rarely is there an immediate turn-around between data collection, analysis and presentation. As a result, most information is old before it is available. The second limitation of data for planning purposes is the level of aggregation. As an example, various types of census information are presented for city blocks and Standard Metropolitan Statistical Areas while other information is presented only for counties. The planner experiences a great deal of difficulty in attempting to combine and/or compare these disparate groupings of information.

These limitations of the data are not nearly as significant, however, as our limitations in using the data. How can all of this data be used and directed at the study of a specific problem? What parts of the data will be most helpful in understanding the past and looking to the future for developmental disabilities? To answer these questions, we need to develop a framework for analyzing developmental disabilities and then collect the data identified as appropriate through the framework.

The Canadian Health Field Concept

All health problems including developmental disabilities, are created through the interaction of a complex set of determinants which may cause problems directly, contribute to the existence of problems, or relate significantly to the occurrence of problems. These determinants can be grouped within four fields as defined by the Canadian Ministry of Health and Welfare.

* *Human Biology:* including all physical and mental aspects of health developed within the individual as a result of his or her basic biology and organic makeup. This includes genetic inheritance, processes of maturation, and internal systems of the body.

* *Environment:* including physical and other factors related to health which are external to the body and over which the individual has little control. This includes foods, drugs, cosmetics, water quality, noise pollution, sewage disposal, and the social environment.

* *Health care organization:* including the quantity, quality, arrangement, nature, and relationships of people and medical resources. It encompasses all providers, institutions, and services of a medical nature.

* *Lifestyle:* involving the aggregation of decisions by individuals which affect their health and over which they have substantial control. Personal decisions and habits which have deleterious effects on health constitute self-imposed risks.[3]

The conceptualization of a problem area in this way gives us an opportunity to not only better understand the problem and its relationship to other factors but to also identify those factors that contribute to the future level of a problem. In this way, more accurate estimates

of the incidence of specific problems can be made since we can begin to identify the impact of other situations on the problem area. It is also possible to identify basic causes of problems that might, themselves, be attacked with intervention strategies designed for the present or the future.

As an example, we can examine infant mortality as a problem area using this concept. The question to be asked is: What causes or contributes to the existence of infant mortality as a problem? Answers to the question are found in all four fields described above and may be obtained by polling experts in the field of infant health. Biological determinants include the age of the mother, congenital malformations, and medical complications of pregnancy. Environmental factors such as poor housing, low socio-economic status, and a lack of family support systems contribute to infant mortality. The availability of pregnancy testing services and the lack of prenatal care services are important health care organization factors influencing pregnancy outcomes. Lifestyle determinants of infant mortality include the nutritional habits of the mother and substance abuse by either parent.

With this list of determinants, a wide range of interventions can be undertaken ranging from immediate efforts to reduce substance abuse among pregnant women to long-range efforts aimed at improving the overall socio-economic status of potential parents. This information can also be used to forecast the number of infant deaths that might be expected given changes in other conditions. If we find that more teenagers are having children and that these children are more likely to experience early mortality, we can more accurately estimate the total number of infant deaths than by merely extrapolating the existing infant mortality rate. If we find, however, that the teenage pregnancy rate is declining, we can expect the overall rate of infant death to decline unless this decrease is offset by an increase in another high risk factor, such as low socio-economic status. This illustration shows the utility of the health field concept for both immediate and long-range planning needs.

In addition to these insights, this framework gives us the advantage of organizing our thoughts about the types of data needed for future planning. Rather than researching the voluminous amount of data related to infant mortality, we have narrowed the field to only ten major determinants. In this way, the acquisition, analysis, and presentation of data can be organized and reduced to a manageable level. We know now what information would be useful and can look at the sources identified earlier to find it.

Applying the Methodology

Quite obviously, this conceptual framework lends itself to specific developmental disability problems and to the challenge of examining the problems from a futuristic perspective. This framework allows us to collect relevant data regarding developmental disabilities and their determinants and then use the data in various ways to forecast the future.

To illustrate this approach for developmental disabilities, consider the problem area of mental retardation. *The Orientation Notebook* for developmental disabilities lists a number of determinants of mental retardation that may be organized around the health field concept.[4]

* Biology
  - maternal age
  - prematurity
  - low birth weight

* Environment
  low socio-economic status

* Health care organization
  lack of prenatal care

* Lifestyle
  maternal diet

While we currently estimate that 3% of the population is affected by mental retardation, this rate may change if there is a substantial change in one or more of the determinants listed above. If overall socio-economic status improved drastically, a reduction in mental retardation would be expected if the rate of occurrence for other determinants remained constant. An increase in mental retardation might result from a change in one of the other characteristics, such as maternal age. We know that maternal age is increasing in the United States. This trend means that more older women (over the age of 35) are having children. Infants born to these women run a greater risk of having a specific condition, such as Down's Syndrome, which could result in mental retardation. Until the mother reaches age 33, the incidence of Down's Syndrome is 1 in 600 live births. At age 40, the percentage of live births afflicted with Down's Syndrome rises to one and at age 45, the percentage is four. Of the children with Down's Syndrome, 90% will be moderately retarded, while 10% will be mildly or severely retarded. A significant change in the number of older women having children after the age of 35 would result in the increased incidence of mental retardation in the population.

An example of the variation in these rates is constructed below for a hypothetical state. The available data show that 5% of all live births in the U.S. in 1975 occurred to women over the age of 35 and that this percentage had increased by 10% since 1970. Preliminary data for 1980 show the percentage remaining at 5%.

In Central State, our hypothetical state, the percent of all live births to women over the age of 35 was 3.6 in 1975 and accounted for 2,911 births. This percentage had remained relatively constant over the last ten years. We can now hypothesize various possibilities for Central State regarding the occurrence of births to older women. We can assume:

a) that the percentage will remain constant for an indefinite period of time;

b) that Central State will follow the pattern established by the United States and experience an increase in births to women over the age of 35; or

c) that an educational program for older women in Central State has been successful in reducing the number of pregnancies experienced by this group.

The following tables illustrate the differences in the numbers of births to women over age 35 that would occur given the different hypotheses. (M.A. refers to maternal age).

Drawing Conclusions

We can now begin to see how different assumptions and interpretations of existing data can lead to different conclusions. The estimates of the increase in the mentally retarded population due to the higher number of women giving birth after age 45, range from 1 to 36 in the year 1995. This range of expectations is reasonable given our understanding of existing data.

Table A: Assume that the percentage of births to women over the age of 35 remains at 3.6:

Year	Total Number of Births	Births to Women Aged 35-44	45+	Children with Down's Syndrome M.A. 35-44	M.A. 45+
1980	75,975	2708	27	27	1.0
1990	82,475	2940	29	29	1.1
1995	90,402	3222	32	32	1.2

Table B: Assume that the percentage of births to women over the age of 35 increases as follows:

Year	Percent of births to women over age 35
1980	3.8
1990	4.2
1995	4.2

Year	Total Number of Births	Births to Women Aged 35-44	45+	Children with Down's Syndrome M.A. 35-44	M.A. 45+
1980	75,975	2859	28	28	1.1
1990	82,475	3429	34	34	1.3
1995	90,402	3580	36	36	1.4

Table C: Assume that the percentage of births to women over the age of 35 decreases as follows:

Year	Percent of births to women over age 35
1980	3.2
1990	2.3
1995	2.0

Year	Total Number of Births	Births to Women Aged 35-44	45+	Children with Down's Syndrome M.A. 35-44	M.A. 45+
1980	75,975	2407	24	24	0.9
1990	82,475	1878	18	18	0.7
1995	90,402	1790	17	17	0.7

We can, however, go a step further by looking at other data to evaluate which of these estimates is most reasonable. For example, consider the following factors:

* More women are entering the labor force with the intention of developing a career.

* Birth control measures are readily available and more effective than ever before.

* The small family is seen as desirable in American society.

* There is a greater emphasis on the quality of parenting and the rights of parents in decisions regarding childbirth.

All of these trends support assumption (b) in the example. The strength of these factors would seem to outweigh the possibilities of maintaining the current rate or of decreasing it through educational programs.

If the process were repeated using the other determinants of mental retardation, such as low birth weight and maternal diet, a number of tables could be constructed from which estimates of the total population could be derived. This approximation would be the result of adding all of the estimates based on the determinants (even though some of them may have a negative value). With this approximation of the total mentally retarded population expected in 1995, we could more appropriately allocate existing resources both now and later for this segment of the DD population.

The same technique can be applied to the other disabilities under the DD umbrella and can provide estimates for human service planners of future possibilities for the DD population.

Footnotes

1 Meadows, D., Meadows, D. L., Randers, J., and Behrens, W., *The Limits to Growth: A Report for the Club of Rome's Project on the Predicament of Mankind.* Potomac Associates, New York, NY 1972. p. 23-24.

2 Health Resources Administration, Office of Health Resources Opportunity publications: *Minority Health Chart Book, 1974; Minorities and Women in the Health Field; Health of the Disadvantaged: A Chart Book.*

3 Ardell, Donald B., "From Omnibus Tinkering to High-Level Wellness: The Movement Toward Holistic Health Planning," *American Journal of Health Planning,* Vol. 1, No. 2, October 1976, p. 17.

4 Hammer, Paula B., and Richman, Gary, *The Orientation Notebook,* Developmental Disabilities/Technical Assistance System, The University of North Carolina at Chapel Hill, Summer 1977, p. 2.3.1.